



**IMPACT OF CROSS-BORDER HEALTHCARE
ON PERSONS WITH DISABILITIES
AND CHRONIC CONDITIONS**





DEFINITIONS

Disability

There is no one, unique and agreed definition of disability. Each EU Member State uses a different definition which causes inequalities for some groups and undermines their right to freedom of movement. The UN Convention on the Rights of Persons with Disabilities provides that 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' ¹.

Disability is therefore understood as the result of the interaction between the individual's impairment and the barriers created by society (be social, environmental and attitudinal).

Chronic condition

Chronic conditions are defined, in a World Health Organization report "Innovative Care for Chronic Conditions" (2002) as "health problems that require on-going management over a period of years or decades" ².

Most chronic conditions are non-communicable, but some are not, e.g. hepatitis, HIV/AIDS, tuberculosis. Mental disorders form a significant portion of chronic conditions.

Regions

The data related to specific countries has been merged into regions for easier representation. The following regions are used in the graphs: Northern Europe ³, Eastern Europe ⁴ and Western Europe ⁵.

Cross-border Healthcare

Cross-border healthcare refers to a mechanism in which the patient from one EU member state (where he/she is insured) uses the health services in another member state. People often seek healthcare elsewhere when a specific treatment is unavailable, the specific care in the other country is considered better or on doctor's recommendation.

Directive 2011/24/EU "on the application of patients' rights in cross-border healthcare" ⁶

This Directive (also called the cross-border healthcare Directive) is of crucial relevance to persons with disabilities and patients with chronic conditions, especially those with specific healthcare needs that cannot be easily addressed at the local level. Articles of particular relevance in this directive to persons with disabilities are Art. 4.2 a) provision of information by the National Contact Point regarding issues such as accessibility of hospitals, Art.6.5. electronic information in accessible formats, Art. 7.4 (para 3) additional costs for persons with disabilities. This directive also makes a provision for set up of European Reference Networks, a formal cooperation between healthcare professionals across Europe in the area of rare diseases.

¹ UN Convention on Rights of Persons with Disabilities <https://goo.gl/KqzwXg>

² World Health Organization 2002, Innovative care for chronic conditions: building blocks for action: global report, p 11. <https://goo.gl/xg1pbh>

³ Finland, Denmark, Sweden, Latvia, Lithuania and Estonia

⁴ Romania, Greece, Hungary, Poland, Bulgaria, Cyprus, Slovakia, Slovenia, Turkey and Czech Republic

⁵ Netherlands, Ireland, Belgium, Spain, Portugal, Germany, UK, Italy, Malta, France, Luxembourg and Austria

⁶ Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross border healthcare <https://goo.gl/sMFc7B>



EXECUTIVE SUMMARY

The International Federation for Spina Bifida and Hydrocephalus (IF) together with the European Disability Forum (EDF) and the European Patients Forum (EPF) conducted a survey among their networks to assess the impact of the Directive 2011/24/EU on the application of patients' rights in cross border healthcare (cross-border healthcare Directive) on persons with disabilities and chronic conditions in the EU. The findings of the survey showed low awareness and low use of the Directive. A vast majority of 85% has never used cross-border healthcare even though 69% of respondents might have used it had they received information about it. Approximately three quarters (77%) of respondents have never heard about the Directive.

One of the key issues is the role of the National Contact Point (NCP) in provision of information to persons with disabilities and chronic conditions. Unfortunately, people very often have no knowledge about its existence, concretely 86% of respondents have never heard about the NCP. Similar lack of awareness as well as low use of the cross-border healthcare Directive has been recorded for both persons with chronic conditions and persons with disabilities.

A particular issue faced by the surveyed groups is reimbursement of costs, especially additional costs, lack of which can lead to discrimination of persons with disabilities who are more likely to need an accessible room for overnight stays or to bring a Personal Assistant. In 76% of cases when additional costs were incurred these were not reimbursed at all because it is not obligatory. However, not reimbursing these costs is contrary to the CRPD principles ⁷ such as those of equality and non-discrimination, which was ratified by all EU Member States except Ireland.

Involvement of representative organisations of persons with disabilities and patients is essential in information provision. They can assist the NCPs on how to provide information to certain patients' groups, they can help the patients with navigating through the complex system while understanding their particular condition. As recent data show only about half of Member States involves patient organisations in information provision ⁸. This is quite the contrary to the position of the EU Commissioner for Health who recently highlighted the importance of cooperation with patient organisations in NCPs' coordination ⁹.

⁷ UNCRPD <https://goo.gl/eop5uk>

⁸ Activity Report EPECS – Implementation of NCPs, p.19 <https://goo.gl/OhPgKU>

⁹ Crossing a border for a medical treatment: Commission publishes data from 23 Member States <https://goo.gl/Uiyysk>

INTRODUCTION

Provision of healthcare is considered an area of shared competence between the EU and its Member States. In practice this means that the EU's powers to legislate in this area are limited. However, the European Commission has substantial powers when it comes to the provision of healthcare across EU borders. In fact, in the interconnected society we live in it is increasingly common that healthcare professionals cooperate across borders. It would be only natural if patients used particular healthcare services outside of their home country as well.

The EU, as well as all EU Member States except Ireland, is a party to the UN Convention on the Rights of Persons with Disabilities (CRPD). The right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability is a fundamental right enshrined in the article 25 of the UN CRPD.

In 2015, the EU progress on implementing the UN CRPD was reviewed by the UN Committee on the Right of Persons with Disabilities. The UN Committee issues recommendations to the EU ('Concluding Observations'). As regards article 25, the Committee 'noted the barriers faced by persons with disabilities in accessing health care in different member States'. It also 'recommended that the European Union (...) evaluate the impact of the European Parliament and the Council of the European Union Directive 2011/24/EU on patients' rights in cross-border health care with regard to gaps in access for persons with disabilities, including accessible information, reasonable accommodation and training of professionals'¹⁰.

Overall, the awareness of the Directive 2011/24/EU "on the application of patients' rights in cross-border healthcare" is very low among the European public: "A recent Eurobarometer survey indicated that fewer than two out of ten citizens feel that they are informed about their cross-border healthcare rights... whilst one in ten knew about the existence of National Contact Points"¹¹. The challenge is dissemination of the information about cross-border healthcare to prospective patients. The information to patients and NCP performances are still source of concerns and continue to be labelled as critical points¹². EU Health Commissioner Vytenis Andriukaitis sees the importance of NCPs and information provision in a similar way as he has recently expressed his regret about the "low awareness among EU citizens of patients' rights to cross-border healthcare"¹³.

To-date there has been no official EU wide assessment of the impact of this Directive on persons with disabilities and patients with chronic diseases, who should be one of the groups of patients likely to use this mechanism. It is unknown how many persons with disabilities have made use of cross-border healthcare and any difficulties they faced. In 2015 the EC published a report on the implementation of the Directive (quoted above), however, the impact on persons with disabilities was missing. In 2018 another such report is due and IF expects that this time a proper impact assessment will be included.

In 2013 when the cross-border healthcare Directive entered into application, IF published its report on Active and healthy EU citizens¹⁴ and 65% of the respondents stated they had no knowledge about the Directive. Now, after the Report on the directive's operation was published in 2015 and before the next one in 2017 is due, IF wanted to assess the situation again. This research is also framed in the context of the CRPD Concluding Observations, where article 25 specifically calls on the EU to "evaluate the impact of its Cross-Border Healthcare Directive with regard to gaps in access for persons with disabilities"¹⁵.

1. METHODOLOGY AND GENERAL FINDINGS



¹⁰ Committee on the Rights of Persons with Disabilities; Concluding observations on the initial report of the European Union, p. 8 <https://goo.gl/dYPZ1q>

¹¹ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, chapter 3, p. 9 <https://goo.gl/Zl6kNX>

¹² Conference on cross border healthcare Directive, 24th October 2016 <https://goo.gl/gqNJH5>

¹³ Crossing a border for a medical treatment: Commission publishes data from 23 Member States <https://goo.gl/Uiyysk>

¹⁴ IF report Active and Healthy citizens, 2013 <https://goo.gl/eeK08p>

¹⁵ EC report Cross border healthcare Member States data, 2015 <https://goo.gl/dYPZ1q>

The survey was developed by the IF secretariat and consulted with a member of IF's Global Expert Panel. At a later stage feedback was given by EPF and EDF. IF disseminated it through social media, IF newsletter, IF website and at events through information flyers. At IF members' workshop in Budapest an information session about the survey was held. EDF shared the survey with its members through weekly mailing as well as with the EDF Expert Group on Health. EPF reached out to 67 patient organisation across the EU through their weekly mailing. The survey was available online from 24 May until 31 August 2016 in English, Spanish, Dutch, Portuguese and Czech.

There were 255 responses, 116 of them were persons with disabilities and 168 persons living with chronic conditions, 50 were parents of children with disabilities and 57 parents of children with chronic conditions. As can be seen from the numbers some people identified themselves as both having a chronic condition and disability. Also, it is important to note that not all the respondents have answered all the questions in the survey as these were not mandatory.

The majority of respondents were female (64%) and over 40 years old (55%). Only very few youngsters took part in the survey (1%). In general, the respondents of the survey tended to be adults with a chronic condition or disability.

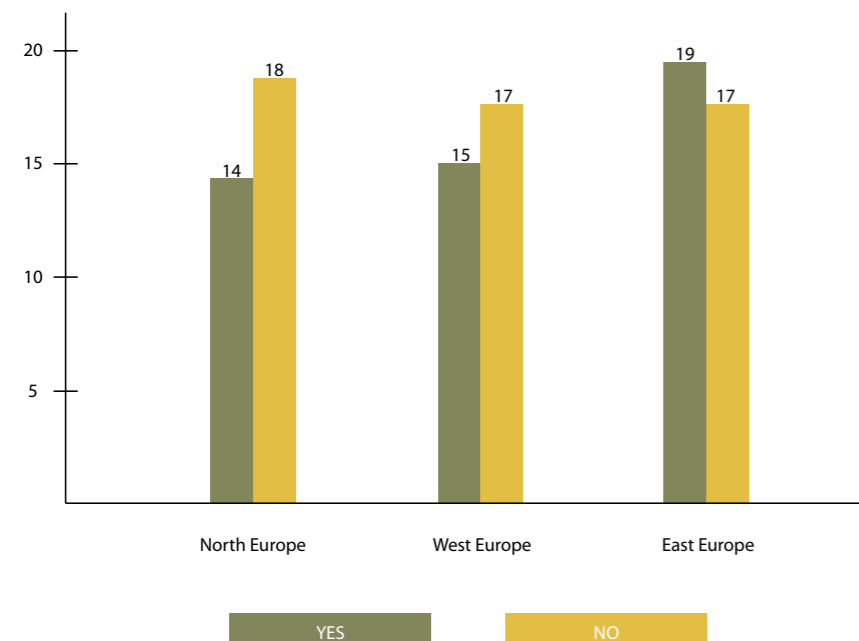
Most answers for this survey were collected from the following countries: Denmark 25%, Czech Republic 21% and Spain 12%. This may have been influenced by the availability of translations into certain languages.

Forty seven percent of all the respondents had heard about cross-border healthcare possibilities. In the following graph you can see the distribution of data with regard to how many people have heard about cross-border healthcare in which region of Europe.

The majority of people that have heard about this come from Eastern Europe (19%). This could be explained by a lack of specialised care in some Eastern European countries, which makes patients search for alternatives abroad. Regarding the use of cross-border healthcare, 85% of respondents had never used it. At the same time almost 69% claimed they would have used it had they been in possession of the appropriate information. Lack of adequate and accessible information will determine whether they will or will not pursue cross-border healthcare with their particular condition.

When people do go abroad for care, in most cases they seek a consultation, followed by a 2nd opinion and next surgery. Reasons for such decisions included better care in another country or availability of treatment in another country that is not available in their home country. In the case of patients with SBH, that would include the availability of multidisciplinary care.

Graph 1: Have you ever heard about cross-border healthcare?



2. AWARENESS OF THE DIRECTIVE



Our survey confirms that there is a low awareness of the cross-border healthcare Directive among its main target groups such as patients with chronic conditions and persons with disabilities; 77% of the completed answers stated that respondents have never heard about this mechanism. Those who did, have mostly heard about it from the European Patients' Forum ¹⁶. Better promotion of cross-border healthcare is needed, as the groups of population most likely to benefit from this mechanism don't even know that it exists.

The awareness of the cross-border healthcare Directive remains very low throughout different age groups regardless of whether the respondents are persons with disabilities or persons with chronic conditions:

%	KNOWLEDGE OF CBHC DIRECTIVE		
	Yes	No	Total
chronic disease	22	78	100% (129 answers)
disability	20	80	100% (87 answers)

Considering the alarmingly low data, it is clear that to achieve a full potential of this Directive for persons with disabilities and patients with chronic conditions, more needs to be done by the European institutions and by the Member States' governments in terms of promotion and information dissemination. This should be pursued with the involvement of representative organisations of patients and persons with disabilities.



3. NATIONAL CONTACT POINTS (NCPs) AND ACCESS TO INFORMATION

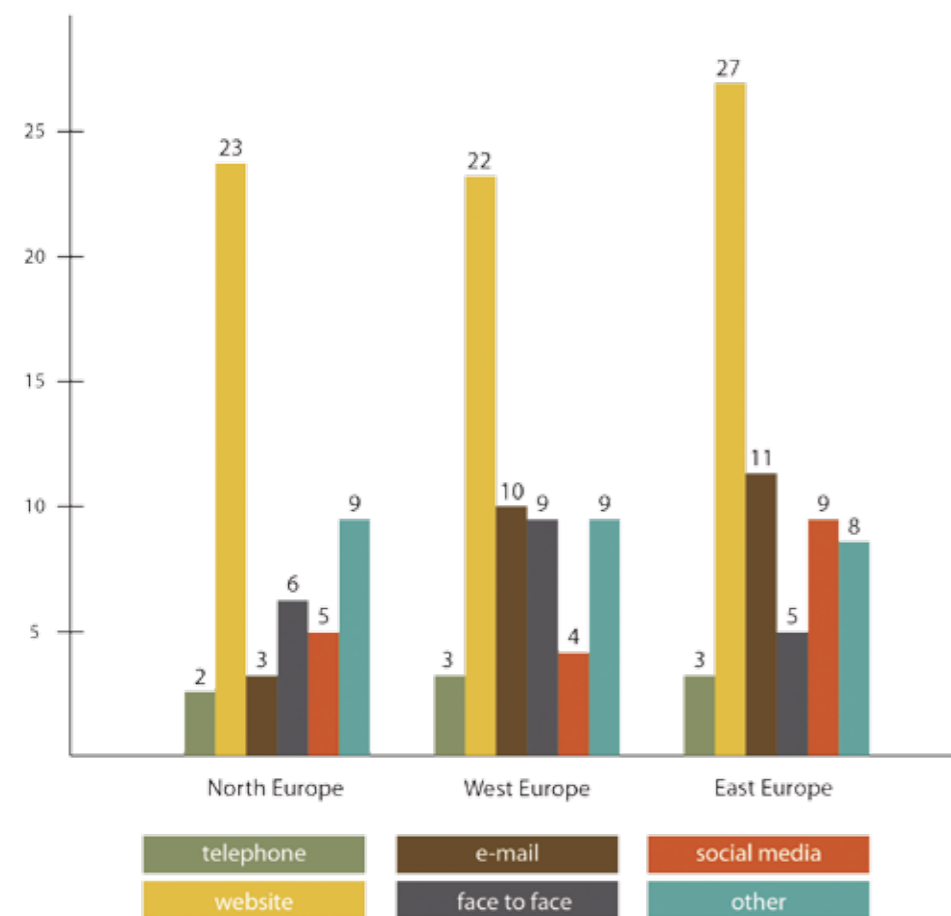
¹⁶ For information about the European Patients' Forum's activities on this topic please see www.eu-patient.eu/whatwedo/Policy/Patients-Mobility/

Knowledge of the National Contact Points among the respondents of the survey was very low, which may be connected to the low awareness of the Directive itself. Eighty six percent of respondents indicated they have never heard about the NCPs.

As we can see in the 2nd graph, people in Northern, Western and Eastern Europe prefer to use a website as channel to access information. It is important to note that 9% of all people also specified that doctors, other families or neighbours can be a good way to access information about cross-border healthcare. A more structured and formalised approach is needed to make sure that the information reaches the patients without having to rely too much on their informal networks. Since it is clear that a website is the most frequently used tool to access information about cross-border healthcare, more resources should be invested into making this information more accessible online, which is currently not the case. Twelve out of 24 NCPs do not provide any format to facilitate the access to their website by persons with disabilities, while Poland and Sweden provide 4 different formats and stand out of the rest¹⁷. There are 80 million persons with disabilities in Europe and many of them will be excluded from cross-border healthcare if they cannot access the NCPs website.

According to the EC report on Data in Member States for year 2015 (published in October 2016) on cross-border healthcare; Poland stands out as receiving by far the most requests for information with a total of 31 736 information requests, almost four times more than any other Member State¹⁸.

Graph 2: Channel to access information



4. USE OF CROSS-BORDER HEALTHCARE, WHERE?

¹⁷ Activity report EPECS – Implementation of NCPs, p.16 <https://goo.gl/OhPgKU>

¹⁸ EC report, p.8 <https://goo.gl/4jpvWQ>

Firstly, the overall numbers for actual use of cross-border healthcare by both persons with disabilities and patients with chronic conditions are equally low. It may be that these two groups face similar obstacles and lack of information.

%	USE OF CBHB		
	Yes	No	Total
chronic disease	14	86	100% (127 answers)
disability	12	88	100% (92 answers)

An overwhelming number of respondents chose to skip the questions related to the experience with cross-border healthcare (between 180 and 214 respondents out of the total of 255). This clearly demonstrates that the majority of them has not in fact used cross-border healthcare and therefore could not answer these detailed questions. Lack of information and language issues were indicated in most cases as barriers to using this mechanism. In this section patient flows between European countries are presented, showing data of those respondents who did use cross-border healthcare.

Seventeen percent of the respondents who did use cross-border healthcare indicated that they went to Germany, followed by 13% who went to Czech Republic and 10% for both the Netherlands and the UK. The role of Germany as a destination for people from other countries seeking healthcare is confirmed by the European Commission's report of October 2016 on Member States data for 2015, which says that "most requests for reimbursement have been granted for treatments in Germany" and the same applies to requests for prior authorisation¹⁹.

More trends on how the country of origin relates to where people go to receive healthcare can be seen in the following table:

COUNTRY OF TREATMENT %	COUNTRY OF ORIGIN		
	Northern Europe	Western Europe	Eastern Europe
Germany	25	7	21
Belgium		7	
Spain		14	
Hungary		7	
Italy		7	
Netherlands		29	
Denmark	25		
Latvia	13		
Lithuania	12		
UK			21
Sweden	25		
Luxembourg		7	
France		22	
(Bosnia and Herzegovina)			5
Czech Republic			26
Austria			16
Slovakia			11
Total	100% (8 answers)	100% (14 answers)	100% (19 answers)

¹⁹ EC report 'Member State data on cross-border healthcare following Directive 2011/24/EU', year 2015, p.4 <https://goo.gl/4jpVwQ>

As this table shows, the majority of patients from Northern Europe stayed in their region for treatment; travelling to countries such as Denmark, Latvia, Lithuania and Sweden, except for 25% of people who went to Germany. Similarly, most patients from Western Europe remained close to home, notably they went to France (22%) and the Netherlands (29%).

Concerning Eastern Europe, over a half of people choose Western Europe as their destination: UK (21%), Germany (21%) and Austria (16%). At the same time, 42% of the respondents who used cross-border healthcare indicated that they remained in Eastern Europe with Czech Republic being the destination for 26%. This may be explained through fluid cross-border exchange and cooperation happening between Czech Republic and Slovakia.

Considering the findings presented in this section, we can conclude that few people (41 out of 255) actually did make a use of cross-border healthcare and indicated where they went. Among those who did, Germany was the most frequent destination, while only few people from other regions sought treatment in Eastern Europe.



5. REIMBURSEMENT OF COSTS AND FUTURE USE

If a person is reimbursed for the cross-border treatment, the more she or he may use it again because it is more affordable. The percentage of people who have received full or partial reimbursement of costs are keen to consider cross-border healthcare again in the future (90% fully, 73% - partially), while those who were not reimbursed at all are less likely.

The reality is that according to the responses of the survey direct costs were fully reimbursed only in 23% of the cases, while 50% of the given responses indicated not getting reimbursed at all. These cases may be because people didn't know how to seek reimbursement, or the care in another EU Member State was not eligible for reimbursement in the Member State of affiliation.

When considering additional costs, 76% of those who used cross-border healthcare were not reimbursed at all. Coverage of additional costs is not compulsory and Member States can decide whether to reimburse these or not. The additional costs, such as bringing a personal assistant or having an accessible room, are of particular relevance to persons with disabilities. When these costs are not reimbursed, the patient with a disability is financially disadvantaged and discriminated in comparison to a non-disabled patient. This is contrary to the CRPD obligations by which the EU Member States shall abide.

According to the CRPD Art.5 on Equality and Non-Discrimination, State Parties shall 'prohibit all discrimination on the basis of disability'²⁰. In addition, Art. 25 of the CRPD states that State Parties shall 'provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons'²¹. A person with disability shall hence benefit from the cross-border healthcare in the same way as others and shall not be discriminated in access to care in another Member State based on disability.

Considering the current situation and the additional financial burden, the patient with a disability or chronic condition may be less likely to use cross-border healthcare again in the future.

The future use can be also linked to the patients' satisfaction with the care as they experienced it, which is shown in the following table.

CBHC - USE AGAIN %	SATISFACTION		
	Yes	No	Total
Yes	81	29	100% (127 answers)
No	0	28	
Not applicable	19	43	
Total	100% (27 answers)	100% (21 answers)	100% (92 answers)

As can be seen, 81% (22 respondents) that were satisfied with the overall experience of cross-border healthcare are likely to use this mechanism again. 40% (12 out of 30) indicated that their main reason for using cross-border healthcare in the future is the 'quality of treatment abroad'.

²⁰ UNCRPD, Art. 5 <https://goo.gl/eop5uk>

²¹ UNCRPD, Art. 25 <https://goo.gl/Oy7Adu>



DISCUSSION - CAVEATS

The purpose of this data collection was to gather solid data among persons with disabilities and chronic conditions on the awareness of cross-border healthcare Directive, its actual use, satisfaction etc. Even though we received responses from 255 people, there was a high number of incomplete answers on the actual experience of using cross-border healthcare, satisfaction and reimbursement. The questions were not mandatory and it is likely that the respondents only filled in those where they had direct experiences. It is important to note that in the beginning of the survey 85% of the respondents indicated they have never used cross-border healthcare. Hence, it is clear that they were not in a position to answer the later question on experience and use.

We could not present a completely accurate account of how many persons with disabilities and how many persons with chronic conditions took part in the survey due to the fact that some people characterised themselves as having both a chronic disease and disability.

Lastly, due to the limited resources at the IF secretariat the survey could only be translated into certain languages apart from English (Czech, Spanish, Portuguese and Dutch) which might have created bias regarding the country participation and influenced the results. Despite this, participation from across the EU was encouraged and most answers (61 out of 243) were in fact received from Denmark.

CONCLUSIONS

Many of the more specific answers were left unanswered by a large number of people, which shows the lack of actual experience with cross-border healthcare. As mentioned in the beginning of this report, an overwhelming majority of the respondents had neither heard about this mechanism nor about the National Contact Points that should be the focal points for information dissemination.

In addition, similarly low figures have been recorded both for patients with chronic conditions and persons with disabilities in relation to awareness of the Directive and use of cross-border healthcare. However, the few people who did use cross-border healthcare and were mostly satisfied and/or had their expenses fully or partially covered reported that they would consider this mechanism again.

The data presented in this report confirms the main hypothesis that led to launching of the survey - that there is a very low knowledge of the existence of the Directive among the surveyed groups of population and that more actions need to be taken by all relevant actors. Therefore, IF together with EDF and EPF would like to propose the following recommendations:

RECOMMENDATIONS

- An EU wide impact of the directive 2011/24/EU on persons with disabilities and chronic conditions needs to be measured and included in the EC report on implementation of the Directive which is due to be published in 2018. Articles to be monitored with particular relevance to persons with disabilities are the following: Art. 4.2 a) provision of information by the National Contact Point (NCP) regarding issues such as accessibility of hospitals, Art.6.5. electronic information in accessible formats²³ and Art. 7.4 on additional costs for persons with disabilities.
- EU wide guidance on the NCPs with common performance criteria should be prepared by the European Commission. The recommendations²² of the European Patients' Forum could be taken as a basis for such guidance, with IF and EDF adding disability specific recommendations. The NCPs have to become active enablers of cross-border healthcare among prospective users with the most need (such as persons with disabilities and patients with chronic conditions).
- The representative organisations of persons with disabilities and patient groups should be involved in this process in order to inform patients of their rights as well as to help them improve their journey overall by working closely with competent authorities and NCP²⁴. Concretely, the representative organisations could highlight challenges to national authorities and the EC and participate in developing solutions. They could also provide feedback to National Contact Points on the services and performance and collect patient stories etc.
- Improve the cooperation between treating doctors and NCPs; doctors should send patients to NCP for information about logistics, reimbursement of cross-border care etc. There should be a straightforward referral procedure in place for this. At the same time doctors should be involved in the European Reference Networks as a way of improving patient care in case of rare diseases. Specialist doctors together with patients and disability organisations could form advocacy alliances in Member States to raise awareness of cross-border healthcare.
- Member states' use of their discretion to reimburse the additional costs incurred during cross-border healthcare must be in line with the UN CRPD in order to avoid discrimination of persons with disabilities and patients with chronic conditions, who are most likely to have additional costs.

²² EPF recommendations on NCP: and position statement <https://goo.gl/oCa24E>

²³ For more information visit EPF website <https://goo.gl/oCa24E>

²⁴ For more information visit EPF website <https://goo.gl/tc1Rtn>



International Federation for Spina Bifida and Hydrocephalus

Cellebroersstraat 16

1000 Brussels Belgium

Tel: +32 (0)2 502 0413

Fax: +32 (0)2 502 1129

E-mail: info@ifglobal.org

Website: www.ifglobal.org



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